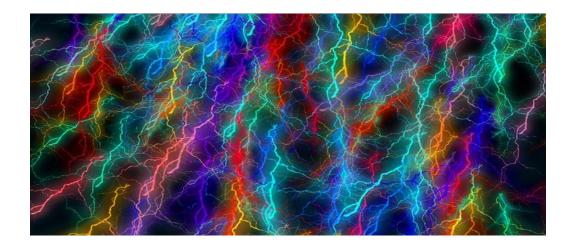


## HUNTINGTON'S SA & NT INC NEWSLETTER. October 2019

## 'Let's Dance'



#### **From the General Manager**

Hello to you all.

What an interesting year to date it has been. As with any Association there is always a great deal of work done behind the scenes and often benefits are not seen for quite some time. The Association is starting to see this pay off. Our challenge has been and we are hoping will continue to be growth.

Those of you who know me know that I prefer to say it how it is and I will continue to do this. Our Political climate of change has not been helpful to the Association and there in lies one of our biggest challenges. We have had to be creative in our thinking and actions hence.

'Let's Dance'™ Which has been successfully trade marked. (why did we do this please see page 4.)

You have probably noticed changes from the usual newsletter and this is due to our volunteer receptionist putting her hand to doing the newsletter this time. Great Job Anna and thank you.

Our Coffee & Co program: This program could not occur without the commitment of many people. A huge thank you to our amazing co-ordinators Julie & Carmen and our volunteers Sonya, Janet and Garry. This program started with 6 attendees and has grown to an average of 32 each week.

Rural Outreach: Has commenced with Whyalla, Port Augusta, Port Pirie and Quorn being visited. I must add that technology is a wonderful thing but nothing beats the face to face approach. It has been an absolute pleasure meeting those that have been visited and I look forward to meeting the rest of you as we visit other areas.

Awareness is such an important part of what we do. In our awareness section Anna has shown that anyone can raise awareness of HD and has the ability to speak out about HD. Well done Anna.

Education: Throughout the rural visits there have been many education sessions given as there have been in the metropolitan area.

Advocacy: Is always and always will be an important part of what we do and is ongoing. Please do not hesitate in contacting the office for our help.

#### Fundraising:

Bunnings at EDWARDSTOWN have been amazing. This connection was commenced 2 years ago and thanks to the tremendous work of Helen Warden-Flood the EDWARDSTOWN activities organizer we have been given ongoing BBQ's for the future and an excellent connection with the Coffee & Co Program. This is a huge gift to the Association. Very few associations get the chance we have been given. I would like everyone to have a think about helping out even if it is only once at a BBQ. The Association is there for our HD community and we will only be there if everyone puts up their hand to help out on occasions. We have a terrific group of volunteers who always put their hands up to help and it would be terrific to see some new faces to help to share the load. It can be a few hours occasionally or regularly. Please consider this.

City to Bay was again a lot of fun and successful. Thank you to all who helped and participated. Hats off to you all.

You will also find a new fundraising kit available on our website shortly. Why not have a read and get together with some friends and see what you could come up with for the Association.

National Associations: On a National level there have been some very positive moves at last to work together as a team to give HD the focus it deserves. On a National level. NSW, WA & Queensland have new CEO's with a great deal of experience in varying areas. There have been 2 meetings with attendance by all states except Victoria. It is refreshing to all be working together for the HD community and a massive step in the right direction.

Volunteers: are the backbone of the Association. We could not function without them. New faces are always welcome. We have a band of those who are always there and to those people I thank you. Kitchen: As many of you are aware the Association was given a new kitchen by the Winkworth's in memory of Nicki's Mum Jen. What they have given to the Association is quite incredible. Along with a grant from the Marion Council for kitchen equipment we now have a functioning kitchen which is used every Wednesday by our Coffee &Co Co-ordinators. The aromas which emanate from the kitchen on these days are amazing.

Marion Council: The council continue to support the Association and we now have a new disability toilet. I am currently negotiating with them for some more work to be done to help with our expansion of activities.

Lastly but by no means least. SACARE. They have taken on the challenge of HD and embraced it. It is an absolute pleasure to be working with those from SACARE in many areas. Thankyou.



Happy reading Michele.

A HUGE THANK YOU TO ALL OUR VOLUNTEERS.
WE COULDN'T DO WHAT WE DO WITHOUT YOU.



## **WEBSITE & FACEBOOK**

Website & Facebook have been improved this year. A big Thank you to Susan who took it on until shifting recently with Michael. A huge Thank you to Milly & Molly from SACARE and Carmen who have taken on tasks across these two areas.

Updating these areas is an ongoing process with changes happening regularly. Keep an eye on these pages.

WEBSITE: www.huntingtonssant.org.au

**FACEBOOK: Huntington's SA & NT.** 



#### 'Let's Dance'™

#### Alongside those with HD

#### Why did the Association choose to use Let's Dance.

We are a small Association, HD does not have a warm fuzzy side like other areas such as

Childhood cancer, diabetes, arthritis etc.

HD used to be known as Huntington's chorea or the dancing disease. Chorea is an ancient Greek word for dance.

After consultation with those with HD and to give the Association an approach to the wider community which people can relate to, puts a smile on peoples faces, makes a person feel great and softens HD we now have 'Let's Dance'™

'Let's Dance ' will accompany all documentation.

#### SOME VERY WISE WORDS FROM THOSE WHO DANCE.

Dancing gives freedom to be yourself, it is powerful, it is relaxing

"You dance love, and you dance joy, and you dance dreams. And I know if I can make you smile by jumping over a couple of couches or running through a rainstorm, then I'll be very glad to be a song and dance man."

Gene Kelly

"When you dance, you can enjoy the luxury of being you."

**Paulo Coelho** 

"If you look at a dancer in silence, his or her body will be the music. If you turn the music on, that body will become an extension of what you're hearing."

**Judith Jamison** 

"It doesn't matter if I'm off the beat. It doesn't matter if I'm snapping to the rhythm. It doesn't matter if I look like a complete goon when I dance. It is my dance. It is my moment. It is mine. And dance I will. Try and stop me. You'll probably get kicked in the face."

**Dan Pearce** 

"Life is short and there will always be dirty dishes, so let's dance."

James How



#### **Our new Kitchen**

Over the past few months the Kitchen ("Jen's Kitchen") has been great, A big Thank You goes out to Nikki and Damien Winkworth for their very generous donation. For the designing, building and construction of "Jen's Kitchen" It is greatly appreciated. WOW it's terrific. The Kitchen is used every Wednesday for Coffee & Co and I know the girls love using it. There's always lots of laughing coming from there, and the aromas coming up the corridor smell wonderful too.











# WE ARE HAVING A WORKING BEE/SPRING CLEAN TO START OFF THE NEW YEAR.

WHEN-January 18th, 2020

WHERE- HUNTINGTON'S SA & NT

ADDRESS- 16 MALWA STREET GLANDORE SA 5037

**WHAT TIME- 0900- 12MD** 

WHAT'S HAPPENING AFTER-

WE ARE HAVING A BARBEQUE LUNCH SO COME ALONG AND ENJOY THE FUN WITH EVERYONE. JUST REMEMBER THE MORE PEOPLE WHO COME

THE QUICKER WE CAN START THE BBQ.





#### **HD COFFEE & CO 2019**

What a success Coffee and Co has been, we started with a few regulars in 2017 and then as of this year we have welcomed many new friends and their Carers and family.



Everyone enjoys the delicious home cooked lunches which are served at the Huntingtons or if we are out and about...lunch comes too!! We are growing our list of activities and to name a few from the last year they include....

10 Pin bowlingA Live BandThe Jam FactoryCraftsChi Ball FunPicnic in the Park

Slot Car Racing Projects with Helen from Bunnings Indoor Winter Olympics

Art with Toni Animal Capers

The Lego Exhibition Barbeques...and many more

We are thrilled to have welcomed volunteers Sonya and Janet who can put their hand to anything and love interacting with the group.

It is also terrific to have a new Kitchen to work in preparing food for Coffee & Co a lot easier.

So come and join us, we would love to meet you!

If anything makes it difficult Eg Transport, ring us and we will do our best to help to make it happen!

#### **CHRISTMAS CLOSURE:**

N.B. Coffee & Co is closing on the 18th Dec 2019 for 4 weeks & will resume in 2020 on Wednesday 15th Jan. From 11:30am to 3:00pm. We hope everyone has a Merry Christmas & a Happy New year.

And everyone has a safe Holiday.

#### Your Coffee & Co coordinators

Julie & Carmen.













### **HD COFFEE & CO 2019**

Wednesdays: 11.30 TILL 2.00 Lunch is provided unless specified

NOVE	MBER	
6th	Spring Racing Carnival Barbeque	At Huntington's from 1130
13th	Adelaide Gaol at 11.00 18 Gaol Rd Thebarton	Tour starts at 12 noon so we need to be finished lunch by then, please make arrangements for your client so this can happen
		Carers :For those on special diets please supply food and drinks, no microwave
		Carers: please bring companion cards
		From south enter from James Congdon, turn R onto Port Rd. Just after Stepney Salvage and Gao Rd. Next Rd. On left
		From north go along Port rd. Towards city and Gaol rd. Will be on your left.
20th	<b>Bunnings Activity</b>	At Huntington's from 1130
27th	Sooz and Chi Balls	At Huntington's from 1130
DECEM	1BER	
4th	Xmas Decorations	At Huntington's from 1130
11th	Xmas Quiz	At Huntington's from 1130
18th	Xmas party -	The Clark Building at Glandore Community centre.  Cnr of Clark & Naldera streets 11.30 till 2.30. More information to be given closer to the date.

**HUNTINGTON'S ADDRESS: 16 Malwa Street, Glandore. 5037.** 

For any queries PLEASE CONTACT: 0424062121 OR Email: michele@huntingtonssant.org.au.

CAN YOU HELP: Trevor is one of our regulars at Coffee & Co. Trevor's mode of transport is his

bike. The kms that he does on his bike would put most cyclists to shame. On his bucket list is his desire to organise a ride for Huntington's.

ARE YOU A CYCLIST OR DO YOU KNOW CYCLISTS WHO WOULD LET TREVOR JOIN THEM ON SOME OF THEIR RIDES AND IF A GOOD MIX BE PREPARED TO CONSIDER ALONGER RIDE IN THE FUTURE.

If you know of anyone could you please let Michele know on 0424062121.



### **Education Sessions for Caring Staff**

Huntington's disease can be a challenge.

If you have someone with HD in care, you are a care provider or an agency you may not know that someone from the Association can come to the facility and give an

HD education session. These sessions have proven to be very helpful to staff not only familiar with HD but those who are new to caring for someone with HD. Huntington's disease is very much an individual disease affecting those with it in different ways which can be quite challenging to those who are in the caring role. The education sessions we provide are tailored to be informative and interactive for staff so any issues that have arisen or may arise for the person in care can have positive outcomes for all concerned.

To book an education session give us a call on 0424062121 or send an email to enquiries @huntingtonssant.org.au



### **HD Awareness**

How many people have you come across who don't know what Huntington's disease is? My guess is there would be quite a few.

Raising awareness of HD is an integral part of the Association and everyone can play a part in this.

Raising awareness can be as simple as wearing an Association T-shirt. When someone asks what is HD tell them. Invite them to come and do some volunteering, come to Coffee & Co and see what the Association does.

As most of you reading this know that the Association is small in the scheme of charities. If everyone let's people know that they are a part of the HD Community word will spread.

Are you a member of, or know someone who is at a university or TAFE, studying areas of health, a member of a Service Club such as Lions, Rotary, Probus Clubs, Schools and Colleges who may be I ooking to expand their awareness, give them our number 0424062121 and we can organize an awareness talk.

Anyone can raise awareness of HD.

"I did a TAFE Course a few years ago an I gave an awareness talk and we decided to do a Fundraiser for Huntington's. The students were great and we raised a bit of money in the process. The Class became more aware of the Huntington's disease, asked a lot of questions and were grateful afterwards. If I can do it anyone can."

Anna Wiren (Receptionist)

So if people would like to help please see Michele or ring the Centre for details.

Phone: 0424 062 121 or Email: enquiries@huntingtonssant.org.au

#### WHAT HAVE WE BEEN UP TO



SACARE is a South Australian, family-owned provider of world-class housing and support services for people living with disability.

They believe that every person should have access to the very best services and accommodation, enabling them to live enriched, fulfilled and independent lives.

Among the many disabilities they accommodate and care for are quite a number of those from the Huntington's community.

Huntington's SA & NT Inc. are excited to be working together in many areas for the HD community.

Thank you to SACARE for your support especially to Milly & Molly, Chloe, Stewart and Andrew.



#### City to Bay Fun Run

September 15th.

OVER \$13,000 raised

A huge thank you to all involved with the City to Bay fun run this year. Over \$13,000 was raised. Our Team came 3rd on the Team fundraiser page. An amazing effort.

A great time was had by everyone. Lots of photos were taken and many of them can be seen at our upcoming AGM on Tuesday October 29th. All involved received a fun certificate. Our grand Champion was Liz Thompson and our Champion of the day Was Chris Warnes who ran in disguise. Congratulations to you both. Thank you to our receptionist Anna for her creativity with the awards.

A great day had by all.

## **HERO QUIZ NIGHT**

James Dean, Amelia Earhart, Elvis, Martin Luther King, Your dad, The Queen,



Neil Armstrong, Marilyn Munroe, JFK, Goofy

Saturday November 23rd

Doors open at 6.00pm

Quiz commences at 7.00pm till 10.00pm

Come dressed as your HERO

& be in the running for some great prizes.

Book your table of 10 or seats. Limited seats available so be quick

\$20/person at eventbrite.com.au/e/77756246025 or

Tickets can be purchased at the door

(If purchasing your tickets on the night please call 0424062121 to book your table or seats as numbers are limited.)

BYO nibbles & drinks

Bring your gold coins & cards for the auction.

Raffle & Auction on the night.

MAJOR AUCTION ITEM: BALI ESCAPE GETAWAY FOR 10.

Where: Clark Building

Glandore Community Centre (Cnr Clark & Naldera St, Glandore)

All proceeds to go to Huntington's SA & NT Inc. to help raise awareness of Huntington's disease.

Let's Dance' alongside those with Huntington's disease.

## HERO QUIZ NIGHT

James Dean, Amelia Earhart, Elvis, Martin Luther King, Your dad, The Queen,



Neil Armstrong, Marilyn Munroe, JFK, Goofy

#### LIVE ON THE NIGHT OUR AUCTION EXTRAVAGANZA



Fancy a Bali Getaway 7 nights for 10 people?

Get your table ready for the bidding.



## If you have never gone to one of these dinners why not give it a go.

## Newcomers are always welcome. It is always great company and good food.

## Monthly Social Dinners Northern Area 6.00PM

Call Brenda on 0421 319 602

Or Stella on 0413 496 025

DATE	LOCATION
4th November 2019	Central Districts Football Club
	Goodman Rd ELIZABETH SA
2nd December 2019	Venue to be Decided

## Monthly Social Dinners Southern Area 6:30PM

Call Fiona on 0424 744 599

DATE	LOCATION
19th November 2019	Crown Inn Old South Road
	OLD REYNELLA SA
17Tth December 2019	Old Noarlunga Hotel
	38 Patapinda Rd
	OLD NOARLUNGA SA



#### **DIARY DATES**



DATE	FUNCTION	TIME			
NOVEMBER					
9th	BUNNINGS BBQ at EDWARDSTOWN	Volunteers always welcome			
23rd	HERO QUIZ NIGHT	Doors open at 6.00. Quiz begins at 7.00 till 10.00pm			
DECEMBER					
Friday 6th	BUNNINGS BBQ at EDWARDSTOWN	Volunteers always welcome			
18th	Xmas Lunch	CLARK BUILDING 11.30 till 2.30. There will be a small			
21st	BUNNINGS BBQ at EDWARDSTOWN	Volunteers always welcome			
	WE HAVE AN AWARENESS TABLE TOO	9.00 till 4.00			
JANUARY 2020					
Saturday 18th	WORKING BEE/SPRING CLEAN TO START THE NEW YEAR AT THE OFFICE	9.00 till 12.00 BBQ to follow.			

CLOSURE DATES FOR COFFEE & CO ARE: Last Coffee and CO is December 18th 2019. Resuming on January 15th, 2020.

OFFICE CLOSURE DATES ARE: DECEMBER 23RD UNTIL JANUARY 13TH 2020



# WE ARE GROWING!!!!! & WE NEED YOUR HELP.

THE ASSOCIATION OFFERS THE OPPORTUNITY FOR SOCIAL INTERACTION, LEARNING NEW SKILLS, GIVING BACK TO YOUR COMMUNITY, RECOGNITION.

DO YOU HAVE A CREATIVE FLAIR OR WOULD LIKE TO LEARN SOME BASIC FLORISTRY. We do up
fresh flowers each week. Come and give it a go. 3 hours on a Thursday or Friday.



OUR MONTHLY BBQ'S AT EDWARDSTOWN BUNNINGS are always full of fun and laughter. We
have 3 shifts each BBQ. Come and join the fun.



OUR COFFEE & CO PROGRAM started with 6. The average each week is currently 30. You have a
great home cooked meal meet those who come along and help out our hardworking
co-ordinators. Everyone who comes along has a great time. Each Wednesday from 11.30 till
3.00. There is always many areas you can help with.



- Many hands make light work and there are always hands welcomed to help set up and pack up any of the above areas or when we have a fundraising event.
  - AFEW HOURS REGULARLY OR OCCAISONALLY CAN GIVE A GREAT FEELING OF SATISFACTION
    KNOWING YOU ARE HELPING THE ASSOCIATION TO CONTINUE TO GROW AND SUPPORT
    PEOPLE, WITH OR IMPACTED BY HUNTINGTON'S DISEASE
  - IF YOU ARE UNABLE TO HELP MAYBE YOU KNOW SOMEONE WHO MAY BE INTERESTED. PLEASE ASK THEM.

**GIVE US A CALL ON 0424062121.** 

### IN LOVING MEMORY

**0F....** 

For those who lost loved ones during the year. Out thoughts are with you. If you know someone who lost a loved one. Our thoughts are with you. Take a moment & see how they are travelling. The impact at the time is hard but often it is down the track that a "How are you going" is much needed.

#### **OUR THOUGHTS ARE WITH YOU.**



### **Contact Details are**

Phone: 0424 062 121

Email: enquiries@huntingtonssant.org.au

Address: 16 Malwa Street GLANDORE SA 5038

Website: www.huntingtonssant.org.au